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The Relationship between Adolescent-Report of Patient-Centered Care and of the Quality of Primary Care

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Abstract

Objective—Few studies have examined adolescent self-report of patient-centered care (PCC). We investigated whether adolescent self-report of PCC varied by patient characteristics and whether receipt of PCC is associated with measures of adolescent primary care quality.

Methods—We analyzed cross-sectional data from Healthy Passages, a population-based survey with 4,105 tenth-graders and their parents. Adolescent report of PCC was derived from four items. Adolescent primary care quality was assessed by measuring access to confidential care, screening for important adolescent health topics, unmet need, and overall rating of health care. We conducted weighted bivariate analyses and multivariate logistic regression models of the association of PCC with adolescent characteristics and primary care quality.

Results—Forty-seven percent of adolescents reported that they received PCC. Report of receiving PCC was associated with high quality for other measures such as having a private conversation with a clinician (AOR 2.2; 95%CI [1.9, 2.6]) and having talked about health behaviors (AOR 1.6; 95% CI [1.4, 1.8]); it was also associated with lower likelihood for selfreported unmet need for care (AOR 0.8; 95% CI [0.7, 0.9]) and having a serious untreated health problem (AOR 0.4; 95% CI [0.3, 0.5]).

Conclusions—Many adolescents do not report receiving PCC. Adolescent-reported PCC positively correlates with measures of high-quality adolescent primary care. Our study provides support for using adolescent-report of PCC as a measure of adolescent primary care quality.

Keywords

adolescents; patient-centered care; primary care; quality measurement

INTRODUCTION

Patient-centered care (PCC) is increasingly recognized as a key component of care quality that should be addressed as part of overall quality improvement strategies. The Institute of Medicine stated in its influential report, "Crossing the Quality Chasm," that PCC is both a core component of well-functioning health systems and a defining element of the patient-centered medical home (PCMH). Conceptually, PCC has been hypothesized to improve health-related patient behaviors such as adherence to care, patient activation and self-management, and engagement in shared decision-making. Sidence is growing for adults that PCC is associated with achieving better outcomes. For instance, PCC is associated with lower readmission rates and greater adherence to treatment plans. Studies in pediatric settings have similarly demonstrated that PCC is associated with better parent-reported experience and improved health outcomes. Furthermore, studies of adults have demonstrated that PCC may help reduce racial and ethnic disparities in the quality of care. PCC is associated with equality of care.

PCC is generally measured by surveying patients about their health care experiences, because patients and families are generally considered the best reporters of these aspects of care. In the primary care setting, items assessing PCC usually address components of care such as how well providers listen, explain things, and treat patients and families with courtesy, respect, and cultural sensitivity. Measures of PCC in pediatrics typically rely on parent report, which can be problematic for adolescent care. Adolescents often see providers without their parent present and keep some of their health care confidential, especially when seeking care for sexual health, substance use, and other sensitive issues.²³ Therefore, parents' perspectives may be incomplete when reporting on adolescent receipt of PCC as they are not privy to all care provided at the visit. In addition, even when parents are present for care, their own and their adolescents' perspectives on PCC might differ. Consequently, eliciting perspectives of PCC from adolescents is important. However, few studies have examined adolescents' own reports on receipt of PCC. In addition, no studies to date have examined whether adolescent self-reported experience of care is associated with other measures of adolescent primary care quality. Thus, we aimed to examine in a community sample (1) whether adolescent self-report of PCC varies by patient characteristics and (2) whether adolescent receipt of PCC is associated with measures of adolescent primary care quality.

METHODS

We analyzed data from Healthy Passages, a longitudinal multi-site study of health among youth. ^{24,25} The Healthy Passages study team conducted interviews of students and their primary caregivers (henceforth referred to as "parents") to assess risk factors, health behaviors, and health outcomes. The participants were initially recruited through public

schools in and around Birmingham, Alabama; Houston, Texas; and Los Angeles County, California. The study team randomly sampled schools with probabilities designed to provide a balanced sample of children who were non-Hispanic black, Hispanic (regardless of race), and non-Hispanic white. Parents of 6,663 out of 11,532 children in sampled schools permitted us to contact them; 5,147 (77%) participated in the study. Parents provided written informed consent; children provided written assent. The baseline wave took place from 2004–2006 when the youth were in 5th grade.

This study analyzes wave 3 data, which were collected five years after baseline, when most youth were in 10th grade. Data for wave 3 were collected in 2009–2011. The retention rate at wave 3 was 86.7%; 4,461 children completed the wave 3 surveys (16.1 [0.5] years). Three hundred fifty-six children were omitted because they were missing information on one of the variables included in the composite measure of patient-centered care, leaving an analysis sample of 4,105. Each parent–child dyad completed computer-assisted personal interviews and audio-computer-assisted self-interviews (for sensitive questions) in English or Spanish. Institutional review boards at the study sites and the CDC approved the study.

Patient-Centered Care

Using items adapted from the Young Adult Health Care Survey (YACHS),²⁶ the Healthy Passages survey asked adolescents to report on four key components of patient-centeredness: whether their doctors/health providers listened carefully to them, explained things in a way that was easy to understand, showed respect for what they said, and spent enough time with them. Answer options included: always, usually, sometimes, and never. Adolescents who reported that their doctor/health provider "usually" or "always" performed all of these four activities over the last 12 months were classified as having received PCC; others were classified as having not received PCC.

Dependent Variables: Measures of Adolescent Primary Care Quality

The items that assessed adolescent primary care quality were also adapted from the YACHS.²⁶ Receipt of confidential care was measured with the following yes/no items: "During the past 12 months, did you get a chance to speak with a doctor or other health provider privately, meaning one on one, without your parents or other people in the room?" and "During the past 12 months, did a doctor or other health provider tell you that what you talked about with them was confidential, meaning it would not be shared with anyone else?"

Provider screening for specific adolescent health-related topics was assessed. Screening for health behaviors included discussing weight, healthy eating or diet, and physical activity or exercise. Screening for drugs and alcohol included discussing substance use (i.e., tobacco, chewing tobacco or snuff, alcohol or drug use) and riding in a car or other motor vehicle with a driver who has been drinking or using drugs. Screening for sexual health included talking about deciding whether or not to have sex and about contraception. Lastly, screening for sexual orientation was assessed by asking whether a provider talked with them about sexual orientation. Screening for health behaviors, drugs and alcohol, and sexual health were each measured through two (drugs and alcohol and sexual health) or three (health behaviors)

summary dichotomous yes/no items where "yes" for the summary variable indicates that providers had discussed at least one of the related items.

Unmet need was assessed by the following two yes/no items: "Has there been any time in the past 12 months when you thought you should get medical care, including a regular check-up, visit for illness or a visit for another reason but you did not?" and "During the past 12 months, have you ever had a serious health problem that went untreated?" For the overall rating of health care, adolescents were asked to rate all of the health care they received from doctors or health providers in the last 12 months from 0 to 10, where 0 indicated "worst health care possible" and 10 indicated "best health care possible."

Independent Variables

Child demographic variables included age, gender, race/ethnicity (Asian, Black/non-Hispanic, Hispanic, White/non-Hispanic, or Other), and insurance status (public, private, or no insurance). Household variables included annual family income (<\$20,000, \$20,000 – \$69,999, or \$70,000) and highest household educational attainment (no high school degree, high school degree, some college, or college degree). Family income was missing for 3.9% of the sample so we included a missing indicator in all multivariate analyses. Child demographic and household variables were obtained from the parent survey. We also included site (Birmingham, Houston, or Los Angeles) as a study-related covariate.

We included a standard indicator of being a child with special health care needs (CSHCN) as an independent variable because health status is known to be associated with report of PCC. These screening items identify children with increased health care needs secondary to a physical, developmental, behavioral, or emotional condition that lasts at least 12 months.^{27–29} In addition, we included adolescent self-reported health status (excellent, very good, good, fair, poor).

Analysis

First, we examined whether adolescent self-report of PCC was associated with patient characteristics. We used chi square statistics to determine bivariate associations between each variable and adolescent report of PCC.³⁰ Patient characteristics included: child gender, age, race/ethnicity, insurance status, highest household education, household income, study site, CSHCN status, and adolescent self-report of global health status. We then built a multivariate logistic regression model to test the association between adolescent report of PCC and patient characteristics.

Second, we examined whether adolescent self-report of PCC was associated with other measures of adolescent primary care quality including measures of confidential care, appropriate adolescent screening, unmet need, and overall rating of health care. We used chi square statistics to determine bivariate associations and then built multivariate logistic regression models to test the associations of PCC with the measures of adolescent primary care quality. We used ordinal logistic regression models to test the bivariate and multivariate association of PCC and overall rating of health care. Multivariate analyses included the following covariates: child gender, age, race/ethnicity, insurance status, highest household

education, household income, study site, CSHCN status, and adolescent self-report of global health status.

We conducted two sensitivity analyses. First, because well child visits are the standard setting for screening, it is possible that associations could occur because adolescents who report having PCC are more likely to have a well child visit. Given this possibility, we re-ran the multivariate analysis limited to adolescents with a well child visit within the last 12 months as a sensitivity analysis. Most adolescents (95.7%) reported having a well child visit within the last 12 months. Second, in addition to our dichotomized PCC variable, we derived an average PCC score across the four items and re-ran the analyses to assess whether dichotomizing PCC was biasing the results.

For bivariate and multivariate analyses, we accounted for design and nonresponse weights, clustering of children within schools, and site stratification using a sandwich estimator and a Taylor series linearization, as implemented by the survey estimation commands in Stata/SE 11.2.

RESULTS

Forty-seven percent of adolescents reported that they received PCC. As shown in Table 1, in bivariate analysis, White adolescents reported PCC more often than Asian, Black, or Hispanic adolescents (Hispanic [39%], Asian [44%], Black [49%], White [58%]; p<0.001) and adolescents with private insurance reported PCC more often than adolescents with public or no insurance (adolescents with private [56%], public [41%], and no [30%] insurance; p<0.001). Adolescents in households with higher education levels and greater household income more frequently reported PCC. Adolescents reported PCC also more frequently with better self-reported global health status (excellent [55%], very good [53%], good [39%], fair/poor [36%]; p<0.001); adolescents with chronic conditions more frequently reported PCC than adolescents without chronic conditions (with chronic conditions [51%], without chronic conditions [45%]; p=0.009). In multivariate analysis, race/ethnicity and chronic condition status were no longer significantly associated with adolescent report of PCC.

Report of PCC was associated with other measures of adolescent primary care quality in both bivariate and multivariate analyses (Tables 2 and 3). On average, adolescents with PCC reported other measures of adolescent primary care quality at higher rates. The largest differences were in receipt of confidential care; 21% more adolescents with PCC report having a private conversation (60% vs. 39%; p<0.001) and 17% more report being told a conversation was confidential than adolescents without PCC (60% vs. 43%; p<0.001). In comparison to adolescents without PCC, adolescents with PCC had a higher odds of having had a private conversation with a health care provider (AOR 2.2; 95%CI 1.9, 2.6) and of being told a conversation was confidential (AOR 2.0; 95%CI 1.7, 2.4). Adolescents with PCC also had higher odds of having talked about health behaviors (AOR 1.6; 95%CI 1.4, 1.8), substance use (AOR 1.4; 95%CI 1.2, 1.7), sexual health (AOR 1.6; 95%CI 1.4, 1.9), and sexual orientation (AOR 1.5; 95%CI 1.2, 1.9). Furthermore, adolescents with PCC had lower odds of unmet need as measured by report of not receiving needed care (AOR 0.8;

95%CI 0.7, 1.0) and having a serious health problem that went untreated (AOR 0.4; 95% CI 0.3, 0.5). Lastly, adolescents with PCC had a higher overall rating of their health care (AOR 2.2; 95%CI 1.9, 2.5). Our sensitivity analysis limiting the analysis to only those adolescents who had reported having a well child visit within the last 12 months (95.7%) did not substantially change our results. Our sensitivity analysis re-running the models using an average PCC score also did not substantially change our results.

DISCUSSION

Although PCC is a pillar of health care quality, more than half of tenth-graders in this community sample of adolescents did not report receiving PCC. Receipt of PCC was most strongly associated with higher levels of household education and higher levels of adolescent-reported global health status. In addition, we found that report of PCC was associated with measures of adolescent primary care quality. Adolescents who reported PCC were more likely to have confidential conversations and be screened for important adolescent health topics. Furthermore, adolescents who reported PCC were less likely to report unmet health care need and adolescents who reported PCC rated their health care higher than those who did not report PCC.

Our study demonstrates that fewer than half of adolescents report receiving patient-centered care. Other studies have found that 67–95% of parents report receiving measures of PCC (e.g., listening carefully, spending enough time), which is higher than what we found by adolescent report. 31–35 In regards to sociodemographic characteristics associated with adolescent report of PCC, our results also show that adolescents were less likely to report PCC if they did not have insurance and were more likely to report PCC if they were from households with higher educational attainment. Bivariate analyses found that Asian, Black, and Hispanic adolescents report receiving PCC less than White adolescents; however, these differences are attenuated in the multivariate model that includes markers of socioeconomic status and health status. The attenuation in our multivariate model suggests that the socioeconomic and health differences might underlie racial/ethnic differences in adolescent receipt of PCC. Our findings are in contrast to the adult literature that has shown that Asian and Hispanic patients often report PCC less than White patients in analyses that control for socioeconomic status. 31 Health status, however, has consistently been found in the adult literature to be associated with report of PCC, 36 and we show similar results for adolescents.

Our study has implications for adolescent primary care more broadly. Although primary care is critical for the health and well-being of adolescents, many adolescents go without the services they need in primary care such as adequate health screening and counseling. 37–50 Adolescents should receive more routine STD testing and emotional and mental health screening. 37,51–55 Studies have shown that only 18% of adolescents reported discussing risky behaviors 37 and that the odds of receiving preventive counseling and screening were higher for adolescents who reported meeting privately with providers. 37,47 Providing confidential care itself is another measure of quality of adolescent primary care. Similar to our study, others have found that no more than half of adolescents report having confidential care. 51,56 Our study suggests, however, that measures such as preventive counseling,

screening, and confidential care are positively associated with report of PCC. Thus, providing PCC could be associated with improving other aspects of adolescent primary care.

As stated above, PCC is also a defining element of the PCMH. The PCMH has emerged as the national standard for providing comprehensive primary care, especially since the passage of the Patient Protection and Affordable Care Act in 2010 (ACA); the ACA funds primary care payment and practice reforms including the PCMH as well as incentives to promote PCMH services.⁵⁷ Measuring PCC is now standard for many practices; for instance, the National Committee for Quality Assurance requires practices to submit measures of PCC to receive PCMH recognition. Further, children who receive care in a PCMH have fewer unmet needs, higher quality of care, and better health outcomes.^{58–60} Our study adds support for PCC as a key component of the PCMH that contributes to these improvements. Adolescent report of PCC illustrates the potential for using adolescent feedback as one measure to determine the efficacy of such efforts.

This study is the first to our knowledge to examine the association of adolescent report of PCC with measures of the quality of the primary care adolescents receive. Our findings are consistent with multiple adult studies that have demonstrated that patient experience is associated with patient behavior (e.g., adherence), clinical processes (e.g., process measures for acute myocardial infarction), clinical outcomes (e.g., mortality), and patient safety (e.g., rate of infections). 2.5,6,61–72 There have been fewer pediatric studies, but they also show similar findings. For example, when parents are less involved in decision-making and receive fewer explanations about their child's care, they report lower quality of care for their child. 73,74 Moreover, poor family-centeredness is associated with increased family stress and higher rates of delayed or forgone care. 17 Our findings add support for the connection between PCC and other health outcomes and emphasize the potential value of adolescent-report of PCC.

Healthy Passages is a large community-based sample of adolescents, but it has limitations. The cohort includes adolescents from three metropolitan areas, so results might not generalize to other populations. In addition, all measures were gathered through self-report by adolescents and their parents. Self-reported measures offer only one dimension of quality of care and like other distinct dimensions, might not correlate strongly with other quality dimensions. In addition, adolescents' experiences of their care, including unmet needs, might also be influenced by factors outside of the healthcare system.

Adolescent self-report of PCC is associated with receipt of better primary care and fewer unmet health care needs. Adolescents often go without the services they need; given the association with other measures of adolescent primary care quality, provision of PCC might increase the likelihood of adolescents receiving other services. Overall, our study provides support for using adolescent-report of PCC as a measure of adolescent primary care quality especially given the emphasis of PCC within the PCMH. Furthermore, given the findings in adults and our findings, efforts to strengthen PCC for adolescents may play a role in addressing disparities in quality of care. Regardless, these findings support asking adolescents directly about whether they receive PCC as a measure of the quality of the primary care they receive. Furthermore, given that over half of adolescents do not report

receiving PCC, improving PCC for adolescents should be a target for future primary care interventions.

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ABBREVIATIONS

AOR adjusted odds ratio

CSHCN children with special health care needs

FPL federal poverty level

PCC patient-centered care

PCMH patient-centered medical home

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What's New

Adolescent-report of patient-centered care is positively associated with measures of high-quality adolescent primary care. Adolescent-reported patient-centered care may be a useful measure of the quality of primary care for adolescents.

 Table 1

 Association of Adolescent-Report of Patient-Centered Care and Key Independent Variables

	BIVARIATE		MULTIVARIATE	
	Weighted % of those with Report of PCC (N=2,030)	p-value	Adjusted Odds Ratio (AOR) of Adolescent- Report of Patient- Centered Care [AOR, 95% CI]	p-value
DEMOGRAPHICS (unweighted n)				
Gender				
Male (2,088)	47%	1.0	REF	
Female (2,017)	47%		0.9 (0.7, 1.0)	0.07
Race/ethnicity				
Asian (92)	44%	< 0.001	0.7 (0.4, 1.2)	0.2
Black (1,359)	49%		1.1 (0.9, 1.4)	0.3
Hispanic (1,276)	39%		1.1 (0.9, 1.5)	0.4
Other (378)	48%		1.1 (0.8, 1.5)	0.8
White (967)	58%		REF	
Insurance status				
Private (2,004)	56%	< 0.001	REF	
Public (1,674)	41%		0.9 (0.7, 1.1)	0.1
None (347)	30%		0.6 (0.4, 0.8)	<0.001
Highest household education				
No high school degree (875)	34%	< 0.001	REF	
High school degree (789)	43%		1.3 (1.0, 1.7)	0.03
Some college (1,121)	49%		1.5 (1.1, 1.9)	0.003
College degree or greater (1,247)	61%		1.9 (1.4, 2.5)	<0.001
Household income			<u> </u>	
<\$20,000 (1,067)	38%	< 0.001	REF	
\$20,000–69,999 (1,672)	45%		1.1 (0.9, 1.3)	0.4
\$70,000 (1,206)	62%		1.5 (1.1, 2.0)	0.04
Missing (160)	36%		0.9 (0.6, 1.3)	0.5
Site			<u> </u>	
Birmingham (1,279)	55%	< 0.001	REF	
Houston (1,405)	43%		0.8 (0.7, 1.0)	0.09
Los Angeles (1,421)	42%		0.8 (0.7, 1.0)	0.06
HEALTH STATUS				
Children with special health care needs (CSHCN)				

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BIVARIATE MULTIVARIATE Weighted % of those with Report of PCC (N=2,030) Adjusted Odds Ratio (AOR) of Adolescent-Report of Patient-Centered Care [AOR, 95% CI] p-value p-value Yes (973) 51% 0.009 1.1 (0.9, 1.3) 0.4 45% REF No (3,119) Adolescent global health status Excellent (891) 55% REF Very good (1,456) 53% < 0.001 0.9 (0.8, 1.2) 0.4 Good (1,272) 39% 0.6 (0.6, 0.9) < 0.001 Fair/Poor (485) 0.6 (0.5, 0.9) < 0.001 36%

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Table 2

Association of Adolescent Report of Patient-Centered Care and Other Measures of Adolescent Primary Care Quality

(N=4,105*)	Weighted % of those with Report of PCC (N=2,030)	Weighted % of those without Report of PCC (N=2,075)	Difference: % with Report of PCC - % without Report of PCC	p- value
CONFIDENTIALITY				
Chance to have a private conversation Yes (2,068)	60%	39%	+21%	<0.001
Told a conversation was confidential Yes (2,157)	60%	43%	+17%	< 0.001
HEALTH BEHAVIORS				
Talked about weight Yes (1,287)	33%	29%	+4%	0.02
Talked about healthy eating or diet Yes (1,645)	45%	35%	+10%	< 0.001
Talked about physical activity or exercise Yes (1,999)	53%	44%	+9%	<0.001
Talked about 1 of above health behaviors Yes (2,296)	60%	51%	+9%	<0.001
SUBSTANCE USE				
Talked about not riding with people who have been drinking/using drugs Yes (1,082)	29%	24%	+5%	0.001
Talked about substance use Yes (1,244)	35%	26%	+9%	< 0.001
Talked about 1 of above substance use topics Yes (1,497)	40%	33%	+7%	< 0.001
SEXUAL HEALTH				
Talked about whether or not to have sex Yes (1,234)	34%	25%	+9%	< 0.001
Talked about contraception Yes (1,485)	40%	32%	+8%	< 0.001
Talked about > 1 of above sexual health topics Yes (1,712)	45%	37%	+8%	< 0.001
SEXUAL ORIENTATION				
Talked about sexual orientation Yes (646)	18%	14%	+4%	0.003
UNMET NEED				
Any time thought you needed care and didn't get it No (2,799)	71%	65%	+6%	<0.001
Serious health problem that went untreated No (3,913)	98%	94%	+4%	<0.001
	Unadjusted Odds Ratio (95% CI)			
OVERALL RATING OF HEALTH CARE	2.7 (2.4, 3.1)			< 0.001

^{*}Minor variation in the N for each variable.

Table 3

Multivariate Analysis of the Association between Adolescent Report of Patient-Centered Care and Other Measures of Adolescent Primary Care Quality*

Dependent Variable	AOR of Outcome for those with Patient-Centered Care in Comparison to those without Patient-Centered Care [AOR, 95% CI]	p-value
CONFIDENTIALITY		
Having a private conversation	2.2 (1.9, 2.6)	< 0.001
Told a conversation was confidential	2.0 (1.7, 2.4)	< 0.001
SCREENING/RISK BEHAVIORS		
Talked about 1 health behavior	1.6 (1.4, 1.8)	< 0.001
Talked about 1 substance use topic	1.4 (1.2, 1.7)	< 0.001
Talked about 1 sexual health topic	1.6 (1.4, 1.9)	< 0.001
Talked about sexual orientation	1.5 (1.2, 1.9)	< 0.001
UNMET NEEDS		
Any time thought you needed care and didn't get it	0.8 (0.7, 0.9)	0.005
Serious health problem that went untreated	0.4 (0.3, 0.5)	< 0.001
OVERALL RATING OF HEALTH CARE	2.2 (1.9, 2.5)	< 0.001

^{*} All models control for: child gender, age, race/ethnicity, insurance status, highest household education, family income, study site, CSHCN status, and adolescent self-report of global health status.